The voices of people with an intellectual disability and a carer about orthopaedic and trauma hospital care in the UK: An Interpretative phenomenological study

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Abstract

Introduction: People with intellectual disabilities (PWID) have a greater prevalence of musculoskeletal conditions and injuries than the general population. Orthopaedic and trauma hospital care has not been investigated with this group who seldom have their voices heard or their experiences valued and interpreted.

Aim: To understand the orthopaedic and trauma hospital experiences from the perspective of PWID.

Methods: A qualitative approach, focusing on peoples' lived experiences, was utilised. A purposive sample of five participants was recruited and one-to-one, semi-structured interviews were undertaken. Analysis of the interviews employed an interpretative phenomenological analytical framework.

Findings: There were communication challenges, a lack of person-centred care, issues with pain management, a lack of confidence in hospital care, valuable support and expertise of carers, incompetence of hospital staff and isolation and loneliness.

Discussion and conclusions: There were significant shortcomings as PWID and a carer perceived they were unsupported and received poor care.

Recommendations for practice: Person-centred care is needed along with specific education and training, including close liaison with the experts by experience – PWID, their carers as well as the specialists in intellectual disability.

INTRODUCTION

This paper presents a qualitative study which explored the orthopaedic and trauma hospital experiences of adults with an intellectual disability. The aim is to share the detailed findings and discuss their application to current orthopaedic and trauma practice.

A person with an intellectual disability is likely to experience difficulty in understanding new or complex information or learning new skills (Royal College of Nursing (RCN), 2017). The person may also have difficulties with social and/or communication skills, with carrying out activities of daily living independently and may have associated physical and sensory disabilities (World Health Organisation, (WHO) 2011). Historically, intellectual disability has been divided into a number of categories that were intended to reflect its nature and extent. These range from 'mild', 'moderate' and 'severe' to 'profound' and generally these have been based on measured intelligence. This represents one understanding of intellectual disability from a medical model perspective. Nunkoosing (2012) asserted that the term 'intellectual disability' is socially constructed, historically and culturally bound, and is used to label a particular group of people within society. Whilst the RCN (2013) describe intellectual disability as a common, lifelong condition which is neither an illness nor a disease, The International Classification of Diseases, (WHO, 2020) (ICD-11) describes intellectual disability as follows:

Disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behavior.

In the United Kingdom (UK), the responsibility and accountability for meeting the health care needs of people with an intellectual disability has moved from large institutions, where people lived separately from the general population and were treated within this environment, to mainstream primary and secondary health care providers (Brown *et al*., 2010). It is evident that people with intellectual disabilities have more health care needs than people without an intellectual disability and they are highly likely to come into contact with hospital services (RCN, 2017).

BACKGROUND

The full integrative review of the literature has been reported elsewhere (reference removed for review). Following the watershed report, 'Death by Indifference' (Mencap, 2007) in which it was alleged that people with intellectual disabilities died as a result of poor hospital care in the UK, there have been numerous reports, policy guidance and legal requirements issued to provide direction for hospital services that support people with intellectual disabilities, for example: Michael (2008); Emerson *et al*. (2012a; 2012b). Despite the legal framework of the Equality Act (2010), there remain significant inequities for disabled people throughout the UK health care system (Tuffrey-Wijne *et al*., 2014a; Tuffrey-Wijne *et al*., 2014b; Sakellariou and

Rotarou, 2017), along with delays in diagnosis and treatment for people with intellectual disabilities (Heslop, *et al*., 2013).

The experience of mainstream health services has been extremely poor for people with intellectual disabilities (Mencap, 2007; Michael, 2008; Heslop *et al.,* 2013). That said, this has not always been the case and there is also evidence to suggest that hospital care has been good for some people with intellectual disabilities. For example, in a study by Howieson (2015) two out of seven participants reported good hospital experiences as they felt that nurses and doctors explained what was happening and they could understand this. There are challenges for people with intellectual disabilities receiving hospital care as hospitals can be frightening and confusing environments; they are often unfamiliar places and people with intellectual disabilities may have had previous negative experiences (Blair, 2017). The importance of supporting people with intellectual disabilities as individuals with the need to give due regard to their human, civil and legal rights is consistently highlighted in the literature. Barr and Gates (2019) asserted that the key principles that must be applied in health care were: people with intellectual disabilities should be valued, helped and supported, actively included and involved in decision-making, have services that take account of individuality and they should have full access to health services. These are the human rights of all people and are mirrored in the ratified United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006).

The population of people with intellectual disabilities has increased with more adults living into older age and many experiencing complex multiple morbidity including a high prevalence of musculoskeletal conditions and injuries (Maulik *et al*., 2011; Kinnear *et al*., 2018). Lifestyle factors are contributors to poor bone health in people with intellectual disabilities, such as poor dietary habits, constipation, poor mobility, low levels of exercise, low levels of vitamin D and obesity (McCarron *et al*., 2011).

Currently no published research investigating the orthopaedic or trauma hospital experiences from the perspectives of people with intellectual disabilities in the UK exists; this study aims to enhance the evidence base in this area of health provision. People with intellectual disabilities represent those previously excluded from research studies and seldom heard (Read and Maslin-Prothero, 2011; Crook *et al.,* 2015; Jack, 2016), hence their inclusion here addresses a critical gap in the extant evidence base.

METHODS AND PROCEDURES

Approach

Interpretative Phenomenological Analysis (IPA) was used to answer the following research question:

How do adults with an intellectual disability describe their orthopaedic or trauma hospital experiences?

The theoretical perspectives of IPA include phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009). This approach provided the most appropriate context for facilitating and 'including the perspectives of vulnerable people' (Gibbs and Read, 2010, p. 233) as it explores, describes, interprets and situates the participant's sense of their experiences (Smith, Flowers and Larkin, 2009). IPA is a qualitative, hermeneutic phenomenological approach (Finlay, 2011) which is relatively new to nursing although there has been a rise in popularity in many academic disciplines due to its useful methodology in studying the existential and illness experience (Finlay, 2011).

The IPA researcher follows the participant in novel and unanticipated directions as the story of their experience unfolds (Smith and Osborn, 2008). A major theoretical underpinning of IPA is hermeneutics, which is the art and science of interpretation or finding meaning. Meaning in this context is deemed to be fluid and is continuously open to new insight, revision, interpretation and reinterpretation. IPA adopts a 'double hermeneutic', in that the researcher is making sense of the participant's sense making thus she assumes a central role in the analysis and interpretation of the participant's experiences (Smith, Flowers and Larkin, 2009). IPA is fundamentally idiographic in that it is committed to the detailed analysis of the phenomenon under investigation (Eatough and Smith, 2006). As an approach, IPA takes great care of each case, offering detailed and nuanced analysis, valuing each case on its own merits before moving to a more nomothetic general cross-case analysis focusing on convergence and divergence between cases (Smith, Flowers and Larkin, 2009). Here we present the results of this idiographic analysis. The cross-case analysis is presented in a separate paper (reference removed for review).

Data Collection: Semi-structured interviews

Semi-structured interviews were utilised (Appendix 1) as this was viewed as the most useful way to gather the lived experiences of people with intellectual disabilities. Prior studies have shown that people with intellectual disabilities can benefit from some level of structure when being interviewed (Gilbert, 2004). The interviews were undertaken between May 2016 and October 2016 by XX. Four interviews took place in person at a location chosen by the participants and one was via telephone. Additional adaptations to the interview process were implemented to facilitate credible data collection (Table 1).

Recruitment and sample

Participants were recruited through the managers of local self-advocacy groups for people with intellectual disabilities and through national organisations that work with people with intellectual disabilities and their health care professional members. The in-depth, idiographic nature of IPA necessitates a small sample size to provide sufficient data to enable in-depth interpretation whilst preventing the researcher becoming overwhelmed by the data (Smith and Osborn, 2008; Hefferon and Gil-Rodriguez, 2011).

Participants self-identified as having an intellectual disability and one participant was the mother and carer for a person with profound and multiple intellectual disabilities and she requested the interview was conducted via telephone. This participant was included to represent the person with profound and multiple intellectual disabilities who the researcher would be unable to interview. All participants had experience of orthopaedic or trauma hospital care. Mental capacity was required to give informed consent to participate along with the need to adequately understand easier read written and verbal information in the English language.

Ethical procedure

Ethical approval was granted by a university Research Ethics Committee in 2014. Given the potential vulnerability of people with intellectual disabilities, a number of ethical issues were considered including informed consent, anonymity and confidentiality, due care and avoidance of coercion to participate in the study along with data storage and protection. Although these principles apply to any research participant, the focus was on the additional requirements for people with intellectual disabilities.

Data Analysis

Data were analysed according to the principles of IPA (Smith, Flowers and Larkin, 2009). Figure 1 shows the stages of analysis.

Trustworthiness was established via several means:

- Purposive sampling alongside thick description of participant circumstances and characteristics
- An audit trail was undertaken for each stage of the research process
- Triangulation was enacted via independent coding and verification of themes by the second and third authors.
- Reflexivity was captured through the use of a research diary.

Figure 1: The stages of data analysis

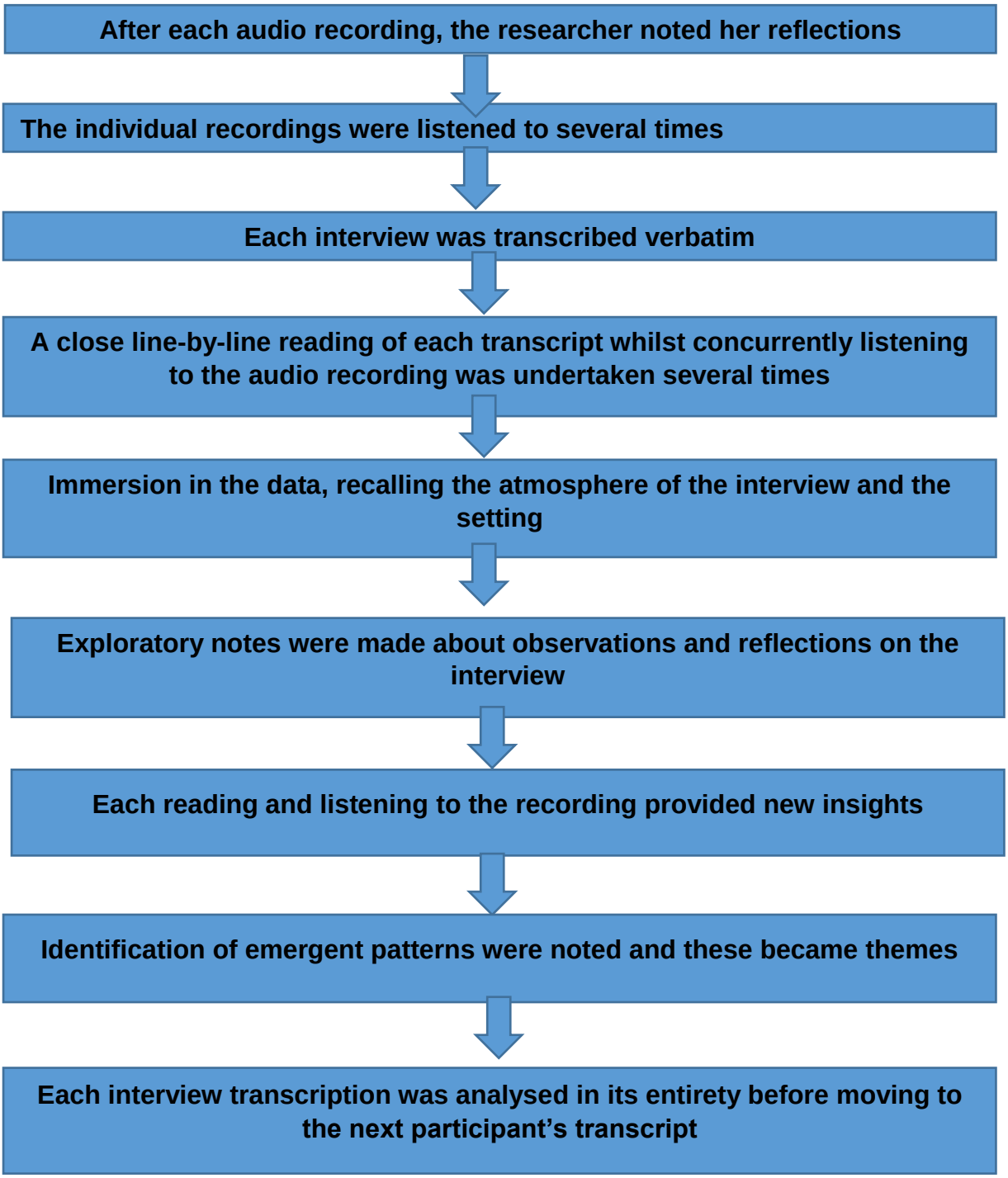


Figure 1: The stages of data analysis

Table 1: Details of the participants

NAME	Gender	AGE	Elective orthopaedic or trauma hospital care	Surgical or conservative treatment	When did the orthopaedic/ trauma hospital care occur?	Adaptations made to interview process	Duration of the interview
Kay	Female	25	Elective orthopaedic	Surgical: multiple operations and hospitalisations for hip surgery Conservative treatment for current knee and spine pain	3 years ago On-going hospital care	Visual aids were used: The Hospital Communication Book	30 minutes
Ted	Male	45	Elective orthopaedic and trauma	Surgical: over 40 operations on lower limbs Conservative treatment for injuries to musculoskeletal system	1991 last planned orthopaedic surgery On-going hospital care for MSK injuries	As Ted had dysarthria, which made comprehension of his speech more challenging, two interviews were conducted one asynchronously via an online messenger and a second face-to-face.	85 minutes
Kelly	Female	32	Elective orthopaedic	Surgical: operation for Slipped Upper Femoral Epiphysis (SUFE) Surgical: total hip replacement Currently awaiting knee surgery	Aged 14 6 months ago On-going hospital care	Kelly asked to have her paid carer accompany her in the interview and Nat supported her throughout the interview.	30 minutes
Len	Male	44	Trauma: Hit by a car at night whilst crossing the road: fractures	Conservative: fractured ankle treated in a below knee plaster cast and then a boot	"A long time ago"	MD met Len at the advocacy group meetings on 3 occasions prior to the interview so the whole group could ask questions and get to know MD prior to agreeing to take part.	24 minutes
Sue (Carer)	Female	Not known	Trauma: son Alex-fractures following accidents	Conservative: Plaster cast for fractured tibia and fibula; Fractures to fingers and toes treated with splints	10 years ago Not reported	As Alex has profound and multiple intellectual disabilities and did not communicate in a traditional verbal way his mother was interviewed to report on their experiences.	45 minutes

*All names have been changed to protect participant identity.

FINDINGS

Table 1 provides an overview of the participants, duration of the interviews and the individual adaptations that were implemented.

The participants' themes

The themes derived from the participants' interviews are presented as individual, idiographic accounts, which aligns with IPA (Smith, Flowers and Larkin, 2009).

Kay

Figure 2 illustrates Kay's themes.

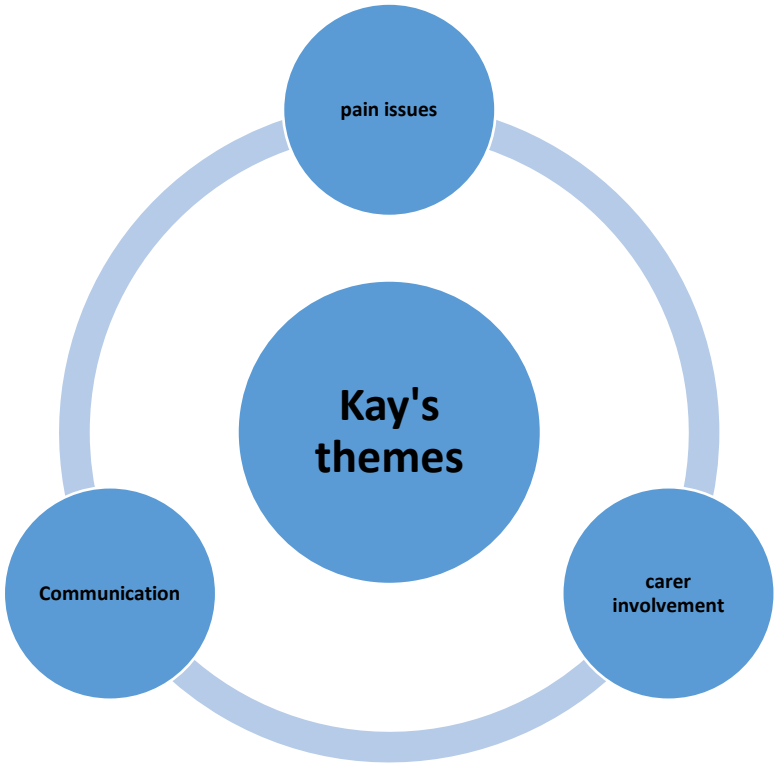


Figure 2: Kay's themes

Pain issues

"Pain" was mentioned numerous times throughout Kay's interview. She recalled being in pain in hospital and waiting for long periods to receive necessary pain relief medication:

…sometimes you have to wait ages for…tablets… when you say you're in pain…they say they're gonna get tablets… they don't come back for ages…and then I end up crying…because I'm in a lot of pain…

(Kay, line 228-233)

Having to wait a long time for the analgesia distressed Kay because she was experiencing a lot of pain. Kay was aware that she should have received the analgesia earlier than she did and she remembered crying because she was in so much pain.

Carer involvement

Kay's mother was very important to her, especially during her hospital admissions, because she helped and supported Kay with fundamental care. Kay waited for her mother to come in to the hospital to help her with washing and dressing and other aspects of care rather than ask the staff to help her. She reported that health staff appeared too busy to support her:

… what they used to do is say…in the morning was have a wash, get ready…but I was scared to ask um to help me…so I just waited for my Mom to come… it was about how busy they are…

(Kay, line 278-281)

Communication

It was a struggle for Kay to understand some of the spoken words used by hospital staff and therefore Kay did not always understand what was happening to her:

…I found it hard to understand… erm… long words…

(Kay, line 373)

Kay relied on her mother to interact with the hospital staff to find out what was happening and then Kay's mother would explain this in a way Kay could understand. As Kay's mother did not stay all the time and there were periods where Kay did not know what was happening to her in hospital:

… but when I…but when I don't understand long words… so sometimes they have to tell my mom and then my mom tells me what it means…

(Kay, line 220-226)

Ted

Figure 3 illustrates Ted's themes.

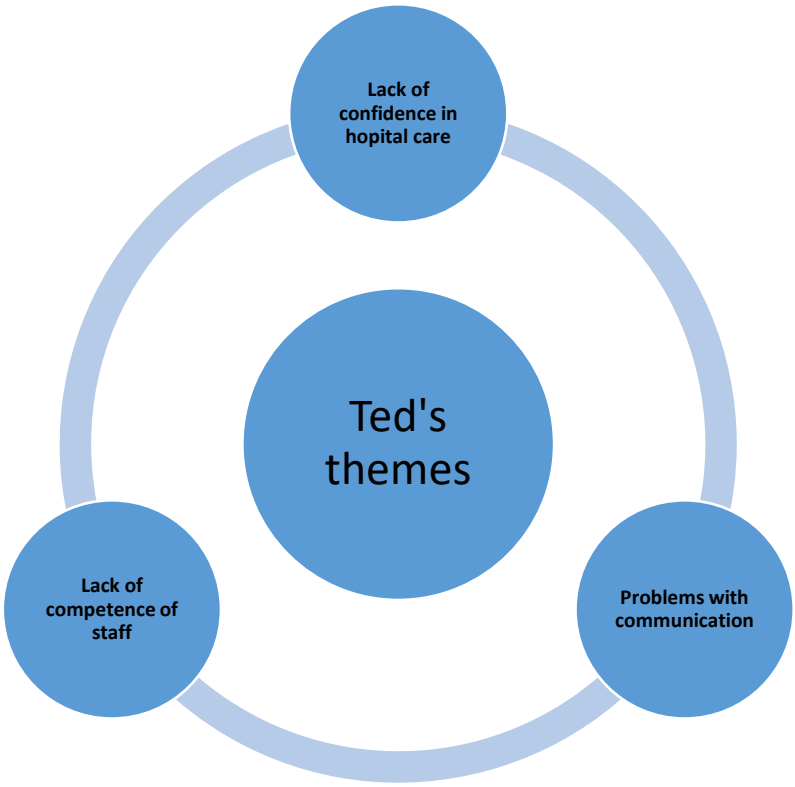


Figure 3: Ted's themes

Lack of confidence in hospital care

Ted had over 40 operations on his legs and he was extremely grateful to one doctor who he said was the only person prepared to try to help him:

…*they said impossible… it wasn't only that … yeah the bones, my hips… like that-* (showing again with his hands that his lower legs were twisted)

(Ted, line 67-72)

…He was the only one who even thought, I will try… I might not be walking now if he didn't try…

(Ted, line 123-125)

Ted was disappointed that only one doctor was willing to operate to correct his lower limbs to enable him to walk. Ted was aware that it was very complicated surgery and if it was not for the belief of that one surgeon, he would still be unable to walk.

Problems with Communication

Ted did not trust communications to him within hospital because he believed that some things communicated to him were untrue or did not make sense:

some said things what made sense but sometimes they said things which were not true or (did) not make sense.

I was not always aware what was happening

(Email from Ted, 13.6.16 at 21:27)

The communication between the staff and Ted was not adapted so as to be consistently comprehensible to Ted; he did not always understand what was happening to him in hospital. Ted received conflicting information about the need to have an X-ray of his nose and this caused some confusion which led to Ted feeling suspicious of the reason why he was sent to an X-Ray department and subsequently sent back to the ward without having the X-Ray:

They said things which were not true

he said they don't do x-rays on noses

(Email from Ted, 13.6.16 at 21:22)

No reason for this inconsistency was communicated to Ted and this affected the level of trust that Ted had in the health care team.

Lack of competence of staff

Ted believed that the hospital staff lacked competence when caring for people with intellectual disabilities and thought that the nurses and doctors required additional and specific education and training:

… nurses and doctors are not trained to look after disabled people… most people in hospital don't have a disabled problem …

(Ted, line 261-264)

Ted also suggested that other staff in the hospital needed education and training, such as the telephone operator, who might be the first contact that a person with an intellectual disability has with the hospital:

…operators are not expecting anyone with any disabled problem to contact them…

(Ted, line 266-267)

Furthermore, Ted was in a room on his own after an operation and he felt isolated as he reported that no-one checked on him for 14 hours:

…in a room on my own…I had blood in my mouth…but no-one came in…it went on for 14 hours… yeah every person had a nurse after their operation… right but I was left for 14 hours …14 hours I didn't see anyone…

(Ted, line 133-141)

Ted was aware that everyone should have a nurse allocated to look after them after an operation but this was not the case for him. Ted felt isolated in hospital and there was no evidence of a caring, therapeutic, person-centred relationship between Ted and the hospital staff.

Alongside this, Ted experienced uncontrolled pain in hospital and although the nurses asked about the pain, he did not feel that this happened regularly. There was an impression that Ted might not have communicated his level of pain to the nurses along with a lack of regular assessment of his pain and appropriate management by the hospital staff:

…sometimes I had very awful pain

…The nurses didn't ask about the pain that often…

(Email from Ted, 13.6.16 at 21:22)

Kelly

Figure 4 illustrates Kelly's themes.

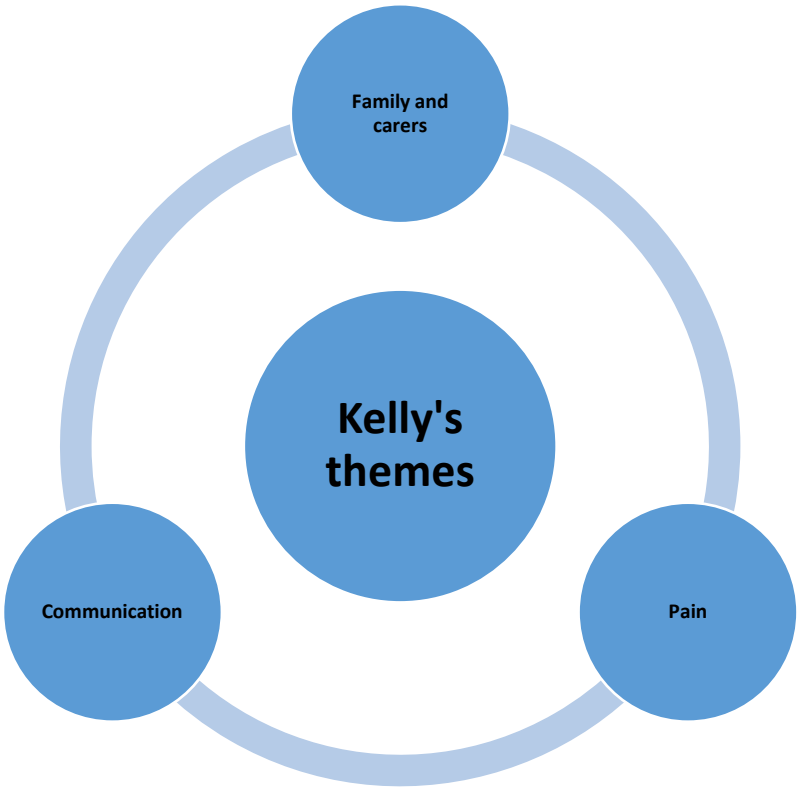


Figure 4: Kelly's themes

Family and carers

Kelly's parents, family and carers were of central importance to her. Nat, a paid carer, accompanied Kelly to a recent pre-operative assessment clinic in preparation for knee surgery and Nat was surprised at the nurse's response to her request to see the intellectual disability liaison nurse:

…we asked the nurse that we first saw, didn't we? But she didn't really know what we were talking about…

(Nat, line 85-86)

Although the role of the acute liaison intellectual disability nurse is relatively new, Kelly received this support in the same hospital six months previously. The nurse in the pre-operative clinic was unaware of the role and did not look further into finding out about it. Nat was knowledgeable about Kelly's support needs and did not accept that there was not an intellectual disability nurse to support Kelly for this next admission to hospital for imminent surgery as she planned to follow this up after the hospital appointment:

… and I asked a physio as well who said she would look into it and get back to me…but…she hasn't…yet…I need to chase it up again but…the social worker was going to look into it as well…

(Nat line 86-88)

Nat believed that she would need to follow this up rather than wait for the hospital to contact her about it.

Pain

At the beginning of the interview, Kelly shared that she no longer had hip pain and there was an impression that she had a great amount of pain before the hip operation. Kelly was pleased with the outcome of this major hip replacement surgery because it eliminated the pain:

no pain…no hip pain

(Kelly, line 6)

Nothing wrong with my hip… the pain has gone

(Kelly, line 31)

Later, Kelly shared an unpleasant experience of when she had removal of the clips from her hip wound:

I had 30 clips in my hip…I was shouting, screaming and crying…I want my Mom and Dad…the nurse did it…

(Kelly, line 266-269)

This was a distressing time as well as a painful procedure for Kelly as she was shouting, screaming and crying for her parents while the nurse removed the clips from the surgical hip wound. Kelly had no control over what was happening to her as the nurse continued to remove the clips despite Kelly's protestations and her request for the presence of her parents. A lack of person-centred care resulted in a very negative experience for Kelly.

Communication

Kelly was confident in asking the nurses to help her with fundamental care, which they did. However, the communication between a doctor and Kelly was unsatisfactory as a doctor spoke to the carer rather than directly to Kelly. This undermined Kelly as a person with a right to be respected and communicated with directly:

…I would say the nurses were good but the consultant, he spoke to me and not Kelly…which I really hate when Doctors do that…just stuff like how old is she…Kelly knows how old she is…

(Nat, line 285-287)

Kelly looked upset as she remembered that a doctor had mentioned about the possibility of her going on to a children's ward rather than an adult ward when she was preparing for the hip replacement surgery:

…I'm 32…and I'm not a child, I'm an adult

(Kelly, line 291-293)

The doctor was talking about the children's ward to Kelly's father prior to her hip replacement with a suggestion that Kelly may go there rather than to an adult ward. Alongside this, Kelly was communicated about rather than with, and the content was inappropriate because Kelly was an adult. The experience of being infantilised within healthcare settings as an adult with an intellectual disability is illustrated within Kelly's account.

Kelly proudly shared how she used an iPhone while she was in hospital to communicate directly with her parents, her carers and friends. Kelly used this

technology, ‘FaceTime’ adaptively to alleviate loneliness and meet her need to be connected with the people she missed while she was in hospital:

‘I used to facetime my Dad…and my Mom…and my Sister…’

(Kelly, line 212-216)

Len

Figure 5 illustrates Len’s themes.

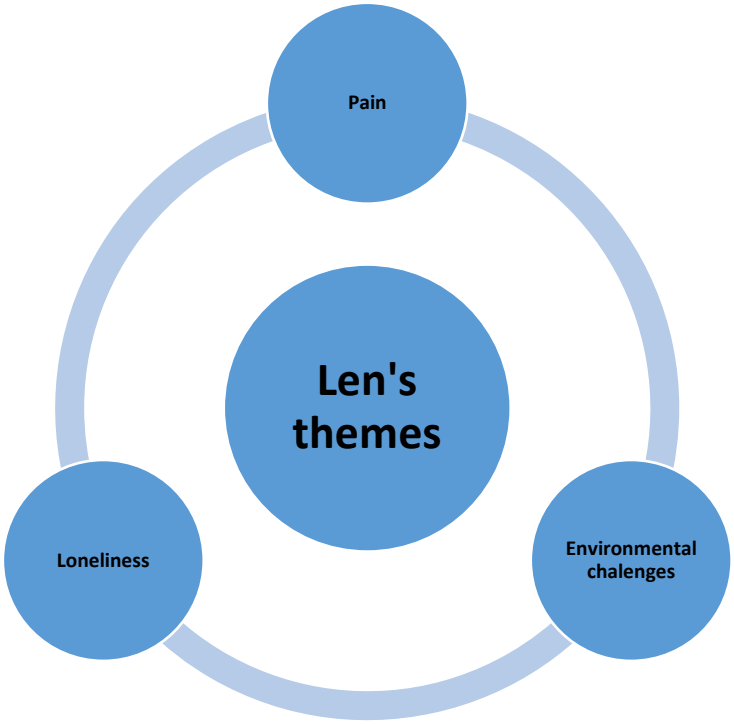


Figure 5: Len’s themes

Pain

After the accident, Len experienced acute pain:

…well…I couldn’t go through the pain and the agony of it…

(Len, line 36)

Len continued to complain of pain in his ankle and accepted this although it was years after the accident:

…well, well erm…erm…I still get aches and pains from it occasionally still…

(Len, line 145-146)

Environmental Challenges

Len disliked the hospital environment as he recalled that it was cold, noisy and lacked privacy:

…horrible…what was it like…absolutely horrible

(Len, line 34)

…it was cold…and not too much privacy neither…noisy

(Len, line 90)

…it was really, really, noisy…you know what hospitals are like…

*(*Len, line 200)

Len was used to living on his own and having privacy but in hospital he had to share facilities on a busy hospital trauma ward. Although Len acknowledged that hospitals were busy, he suggested that hospital staff need to listen to people like him who were disabled:

…erm…listen to what we say…more about our rights… that we're disabled… and understand

(Len, line 180-186)

Len felt that he should be listened to much more in hospital, particularly as he was a person with a disability. Len knew he had rights as a disabled person and he did not believe that hospital staff were aware of these rights or really listened to people with disabilities in this busy environment.

Loneliness

There was a sense of loneliness throughout Len's account as he felt isolated once he returned home from hospital; he did not leave his flat because he thought he could not go out:

…it was horrible…I couldn't go out to places neither when I did it...I had to be stuck in the flat all the time, didn't I... all the time basically

(Len, line 64-66)

Sue

Figure 6 illustrates Sue's themes.

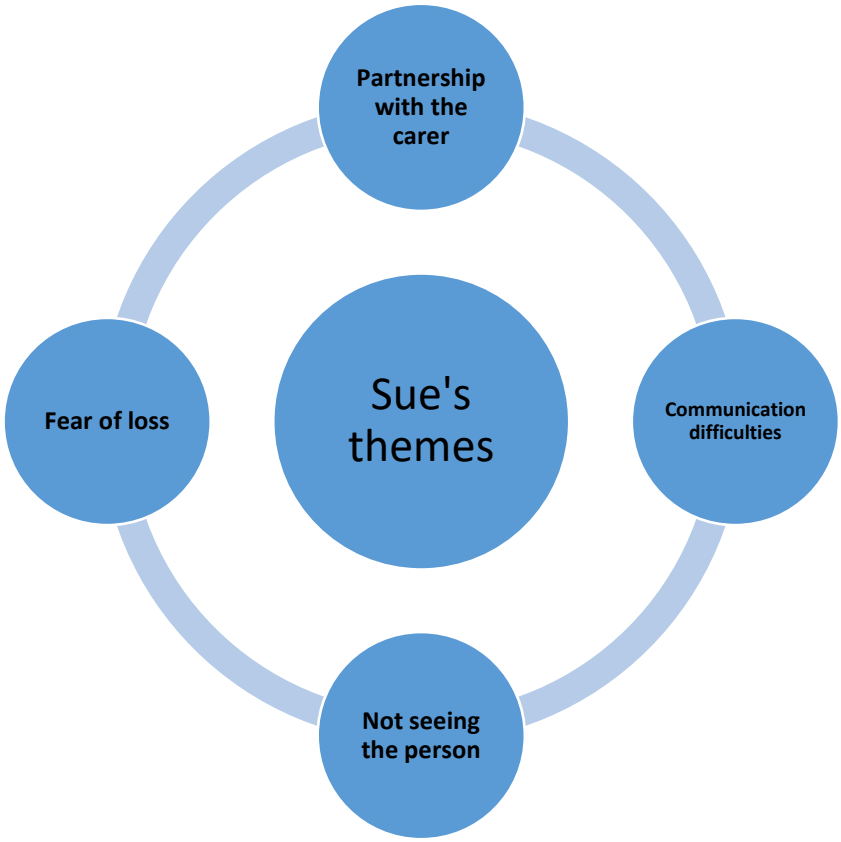


Figure 6 Sue's themes

Partnership with the carer

Sue undertook most of the care for Alex in hospital and rarely left him alone. However, she was aware how exhausted she became and highlighted that carers must be enabled to sleep in hospital too:

…and I think the carers take on so much…you need to sleep too as you can end up exhausted at the end of it all, so take care of the carers too…

(Sue, line 443-444)

Sue did not feel supported in the hospital and it was evident that Sue and the nurses did not work together. As Sue knew and understood Alex better than any of the hospital team, she believed she was as an asset and she could help the team to

understand and care for Alex. Sue did not believe the nurses actively listened to her or respected her as an expert in caring for Alex:

…having nurses that listened, actually took notice of what I said, that I'm not just this mother, that I actually have some information that could be helpful and that they could work WITH me and not me feeling I had to work against them all the time…

(Sue, line 479-482)

Communication difficulties

Sue believed that Alex understood verbal communication although he was unable to communicate verbally and she had explained how to communicate with Alex to staff:

…they had a go…um….and I explained to them all that… how he smiles for yes and frowns for no and that he understands everything that you are saying and stuff…yeah they did have a little bit of a go but pretty ineffective really …

(Sue, line 425-428)

Although staff attempted to communicate with Alex, Sue felt it was ineffective overall. Moreover, Sue felt that Alex was ignored in hospital because he did not speak and she felt that he was not valued as a human being:

…*you know because they just seem to think that he's not [human], that he's stupid or something…he doesn't answer or say anything but he might one day…*

*(*Sue, line 262-263)

Not seeing the person

Sue was extremely dissatisfied with the care Alex received and compared this with the care that her other son, Alex's twin brother, George (who did not have an intellectual disability) received when he fractured his tibia and fibula:

…*gross isn't it? Compared then with my other son, I can take any number of his incidences…broken legs and stuff… um… so I can take one where it was a fairly comparable injury in fact due to his bike and he came off his bike and was in a heap…and he was screaming and he was like screaming and so I said stop screaming and tell me what's wrong…and he could tell me …he could tell me what was wrong so I said um…you can hop on one leg, can't you? Then I can pick you up and you can hop over to the car and we can get you to the hospital…but it hurt too much and I couldn't move him at all…so the ambulance came and they strapped him up before they moved him and… and put him on a stretcher and took him straight to*

hospital… but he was treated straightaway…no question about, oh he's never going to walk on it…there was no question of anything like that at all…

*(*Sue, line 215-235)

This episode of care and treatment for her other son who sustained a similar fracture to Alex was fundamentally different to the care and treatment that Alex received. The emergency staff treated Alex's twin brother immediately and appropriately with a splint. Sue believed that Alex's care was inferior to the care and treatment that her other son received because George could speak and did not have an intellectual disability. Sue's account highlighted the inequity of care provision for Alex who was seemingly viewed as less human in the orthopaedic and trauma hospital setting.

Fear of loss/dying

Sue felt an overwhelming lack of concern in hospital for Alex and ultimately she was fearful that he would die if he stayed there. Sue was exhausted and exasperated during the period of Alex's care due to a lack of appropriately and reasonably adjusted care:

…He'd have died if he'd have stayed in hospital… He'd have died

(Sue, line 414-416)

DISCUSSION

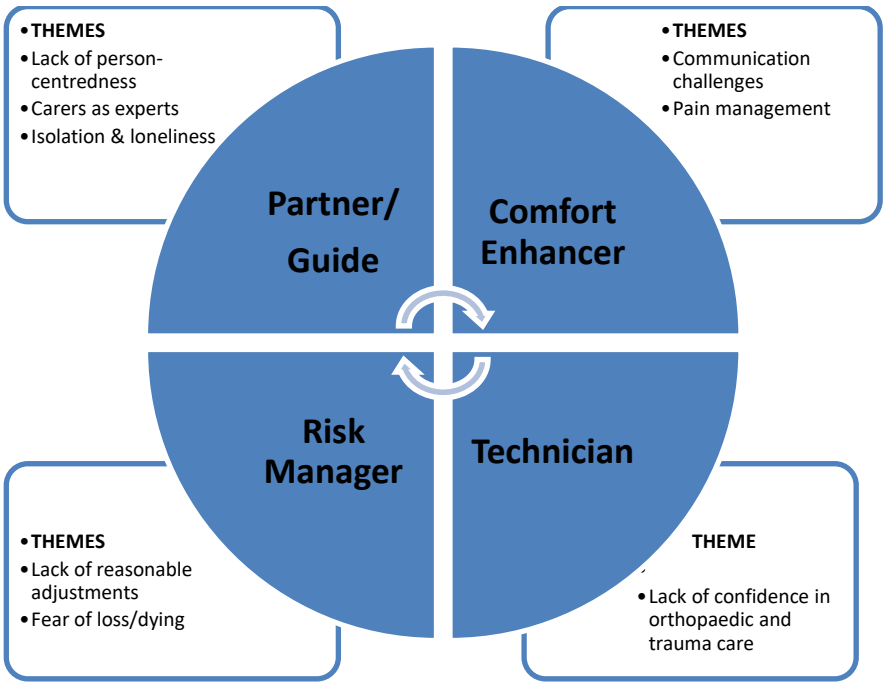
This study provided an opportunity for people with an intellectual disability and their carers to "tell it as it was" so that an understanding of the richness of their orthopaedic or trauma hospital experiences could be gained (Jack, 2010, p. 5). An overall lack of person-centred care impacted on the communication challenges that the participants experienced which in turn influenced the effective assessment and management of pain, issues of isolation and loneliness which negatively affected the confidence and trust the participants had in the orthopaedic and trauma hospital system.

The RCN Society of Orthopaedic and Trauma Nurses national competencies (RCN, 2019) provide an evidence-based framework which guides the education, training and practice of current and future practitioners of all levels. The findings from this study accord with the four key domains of the existing competency framework and thus have been mapped to it to illustrate their direct relevance to orthopaedic and trauma practice.

A competency framework for orthopaedic and trauma practitioners caring for people with intellectual disabilities

The key findings from this study have been mapped to the RCN Society of Orthopaedic and Trauma Nurses (SOTN) competency framework (RCN, 2019). Figure 7 shows how the findings have been mapped across the domains of practice.

Figure 7: The themes derived from the study situated within the domains of orthopaedic and trauma practice (RCN SOTN 2019)



Partner/Guide

The 'Partner/Guide' domain entails the building of a person-centred relationship to support patients to achieve optimal clinical outcomes. A primary function and the goal is to assist patients, in partnership with the family, to gain a level of mobility and activity that meets their potential (Santy *et al*., 2005).

Lack of person-centredness

McCormack and McCance (2010, p. 13) describe person-centredness as:

'An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right

to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development'.

Although the terms 'person-centred care' or 'person-centred practice' remain prevalent in health care literature, policies and codes of practice, this study found that orthopaedic and trauma hospital care was not person-centred for any of the participants.

Carers as experts

Kay and Kelly had significant carers in hospital and relied on them for support. Although Sue was an expert carer by lived experience, she felt conflict when she challenged staff regarding the inadequate care delivered to her son. Mencap (2012) concurs that families of people with intellectual disabilities have provided round-the-clock nursing care and that they were very concerned for their relative's wellbeing to leave their side in hospital because if they were not there, fundamental tasks such as feeding, providing drinks, washing and changing would not meet that person's basic needs. Tuffrey-Wijne *et al.* (2014a) also found a lack of support for carers of people with intellectual disabilities in hospital.

Isolation and loneliness

Len and Ted did not have family or paid carers with them in hospital and both lived alone at home. They were the only male participants in this study and Ted reported feeling isolated in hospital when he was in a side room. Len emphasised how lonely he was when he went home alone with no support. He felt unable to go out or meet up with his advocacy group due to the boot on his lower limb and he felt lonely. Specht *et al*. (2018) found, in their qualitative exploratory study with patients who did not have intellectual disabilities, that the participants also experienced a lack of support once discharged home from a fast track/enhanced recovery/early discharge from orthopaedic hospital care. As far back as 1996, Lovett recognised the significance of relationships for people with intellectual disabilities and more recently, Crickmore and Marsh cited in Barr and Gates (2019) acknowledged that everyone needs the support of other people throughout their lives although people with intellectual disabilities often lack this support from friendships and rely more on services.

Comfort enhancer

The 'Comfort Enhancer' domain relates to the comfort enhancing practices, such as competence in the positioning of limbs and the assessment and management of pain to promote comfort for patients with orthopaedic conditions or injuries.

Communication challenges

There were problems with communication for all of the participants whilst receiving orthopaedic and trauma hospital care. The potential ramifications of poor communication between health care staff and patients can lead to increased fear, anxiety, non-compliance with treatment and an increased risk of complications (McDonald, 2016) which can lead to a lack of trust in the nurse also.

The Accessible Information Standard (National Health Service England, 2018) reinforces that people with intellectual disabilities need to be given information in a way they can access and understand and this is a disability related reasonable adjustment. Health care practitioners need to understand inclusive communication and how they can make reasonable adjustments to their communication style to meet the needs of people with intellectual disabilities (Kwiatek and Valentine cited in Barr and Gates, 2019).

Pain management

There was an interconnection with communication and pain because pain assessment and management rely on good communication. All of the participants who were patients experienced unmanaged pain in hospital. Pain is well known to be a prevalent symptom in people with orthopaedic conditions or injuries (Mackintosh-Franklin in Clarke and Santy-Tomlinson, 2014). The majority of the participants were able to report their pain verbally and it was unsatisfactory that they felt this was not managed effectively.

An important aspect of an orthopaedic nurse's role is pain recognition, assessment and treatment (Hall and Gregory, 2016) and Gregory (2017) highlighted that this was particularly poor with elderly patients and people with cognitive impairments in orthopaedic trauma hospital settings. Pain must be assessed and managed to prevent the ongoing and unanticipated consequences that poor initial management is now known to lead to a lifetime of chronic pain for many patients (Mackintosh-Franklin 2018).

Moreover, Cooper *et al*. (2014) contend that if nurses are unaware of specific assessment tools for use with people with an intellectual disability then pain may be missed and distress increased. There are tools available to assist staff in assessing pain when people with an intellectual disability cannot communicate verbally, such as the Disability Distress Assessment Tool (DISDAT) (Regnard *et al*., 2003; 2007). This tool, used in conjunction with carers' knowledge and appropriate training, can be used to minimise unnecessary pain.

Risk manager

The ‘Risk Manager’ domain identifies the specialty and general risks or complications that need to be minimised for patients receiving orthopaedic or trauma care. ‘Diagnostic overshadowing’ is a term used to describe a situation where signs and symptoms in people with intellectual disabilities are overlooked due to the person’s intellectual disability (Blair, 2017) which can result in life or limb threatening complications for a person with an intellectual disability.

Lack of reasonable adjustments

There is a legal requirement for hospitals to respond to the needs of individual disabled people by anticipating individual need as well as making reasonable adjustments, for example, services should pre-plan changes that may be needed such as the timing or length of an appointment, or ensuring that a family member can be involved in the care (Equality and Human Rights Commission, 2015; MacArthur *et al*., 2015).

Fear of loss/dying

Sue believed that her son would die if he remained in orthopaedic trauma hospital care. Glover *et al*. (2017) identified that people with intellectual disabilities have an expected life expectancy at birth 19.7 years lower than the general population and the Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) (Heslop *et al*., 2013) highlighted that people with intellectual disabilities were dying prematurely and that many were avoidable if appropriate and timely interventions had occurred. Consistent with this, Northway *et al*. (2018) found that most of the recorded deaths of people with intellectual disabilities occurred among those who were middle aged.

Technician

The final domain in the RCN SOTN competency framework is that of the ‘Technician’ which relates to the complex nature and management of the external appliances and devices that are used in the orthopaedic or trauma speciality.

Lack of confidence in orthopaedic and trauma hospital care

The technical components of caring for Alex who required support for all his needs was lacking in hospital. Sue undertook all aspects of her son’s care including feeding, washing, positioning and bowel care because she felt the nurses did not have the knowledge or understanding to do this competently. This lack of trust, confidence and belief in the hospital staff to adequately care for her son with a profound and multiple intellectual disability (PMID) who had a fracture to his tibia and fibula, a common injury, was extremely disappointing and contrary to the aims of the NHS which promotes high quality of care for all (Department of Health, 2009).

Strengths and limitations

- A major strength of the study has been the inclusion of people with an intellectual disability as participants; they are often excluded due to perceptions of difficulty in obtaining ethical approval and need for extra time/resources to facilitate their inclusion and previously their voices have been absent from patient experience focused research about orthopaedic and trauma hospital care.
- The design of the study enabled people with intellectual disabilities to share their experiences and the methods employed provided a detailed analysis of these experiences.
- The findings extend understanding of the experiences of people with intellectual disabilities in orthopaedic and trauma hospital care.
- Varying time periods between hospital experiences and being interviewed may have impacted on re-call.

CONCLUSIONS

This is the first study to explore the orthopaedic and trauma hospital experiences from the perspectives of people with intellectual disabilities and a carer of a person with a profound and multiple intellectual disabilities. The contribution to new knowledge is that there was a distinct lack of person-centred care; there were challenges with communication; there was a lack of assessment and management of pain; the negative experiences included feelings of isolation and loneliness and a lack of confidence amongst people with intellectual disabilities and a carer regarding orthopaedic and trauma hospital care; the expertise of carers was not adequately tapped or acknowledged by hospital staff and a family carer feared that her son would die if he remained in orthopaedic trauma hospital care.

Recommendations for practice

- A targeted focus on the delivery of person-centred care for people with intellectual disabilities in orthopaedic and trauma hospital settings.
- Specific education and training for orthopaedic and trauma care practitioners.
- Close liaison with people with intellectual disabilities, who are experts by experience, their carers as well as specialists in intellectual disability such as learning disability nurses and organisations that work alongside people with an intellectual disability.

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Appendix 1: The semi-structured interview guide

Welcome and background to the study. I will have easier read literature, symbols and pictures to explain and give to the participant prior to and during the semi-structured interview. I aim to create and maintain a relaxed and friendly environment.

Introductions

The researcher will go through the informed consent form again using easier read materials, symbols and pictures, allowing extra time for explanations and repetition prior to the interview. I will explain the researcher's role and the plan for the 30-60 minutes

Background information (to collect for context)

Age:

Sex:

Where do you live? (Town/County)

Who do you live with?

Questions

1. Have you been in hospital before?

Prompts:

Which hospital did you go to?

When was it?

Reason for hospitalisation/ broken bone/other injury/planned surgery?

When was this/months/years ago?

How long were you in hospital-days/weeks/months?

2. What was it like for you?

Prompts:

What was the ward like?

What did you like/dislike most about it/ the food in hospital/ were you able to move/eat and drink/get dressed/get to the toilet?

Did you have crutches (if lower limb affected)/cast on/sling (if upper limb affected)?

Did you have pain? What helped the pain?

What was good about the ward?

Were the staff helpful/kind/unhelpful/unkind, any examples?

Did you have the same person caring for you? Was it friendly/unfriendly, any examples? Did the doctors and nurses talk to you? Can you remember what they said?

What did they say?

3. What would have made your stay in hospital better?

Prompts:

What helped?

Did you feel happy/unhappy?

Did you feel safe/unsafe?

Cared for/uncared for?

Do you have any examples?

Did you feel well/ not in good health when you went home from hospital?

4. Have you been feeling well since your hospital stay?

Prompts:

is the bone fixed?

Do you have any pain from the surgery/operation/treatment now?

Can you do things that you like doing more/less since the operation/surgery?

Did you have an appointment with the hospital after you went home?

Thank you for taking part.

When I listen/read what we've talked about, I might need to come back and talk to you again about some things, would that be ok?

Debrief- At the end of the interview the researcher will go through a debrief explaining again what the study is about and how the data will be treated and reported and will check that the person still wishes to take part. This will be based on the participant's level of communication and interaction and will be altered accordingly.